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THE RELATIONSHIP BETWEEN THE CAREGIVER BURDEN AND THE QUALITY OF LIFE OF THE CAREGIVERS OF THE PATIENTS SURVIVED FROM STROKE IN TABRIZ UNIVERSITY OF MEDICAL SCIENCES SPECIALIZED CLINICS

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ABSTRACT

Background and objective: stroke is one of the most common chronic diseases, the third cause of death in developed countries, and the main reason for disability in adults. The caregivers of the patients survived from stroke would face physical and mental problems, insufficient rest, changes in social communication, employment status, and economic problems. The objective of this study was to investigate the relationship between the caregiver burden and the caregivers' quality of life.
Method: this is a descriptive correlational study conducted on 120 caregivers of the patients survived from stroke who visited Tabriz University of Medical Sciences clinics through the instruments included Caregiver Strain Index (CSI), the Iranian version of the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire and the demographic information questionnaire in 5 months. The validity of the questionnaires was determined by content validity and the reliability of which was determined by Cronbach's alpha. The relationship between the caregiver burden and the quality of life was investigated through Pearson correlation test in SPSS 24.
Findings: in this study, most of the caregivers were the children of the patients with an age average of (41.9±12.38). The minimum score of the quality of life mean belonged to environmental health (57±16.74) and the maximum score of which belonged to physical health (79.74±16.48). The minimum caregiver burden was 5 and the maximum of which was 13. There was a significant relationship between the caregiver burden and quality of life regarding the aspects of physical health (r=-0.405 and p=0.01), mental health (r=-0.227 and p=0.007), and environmental health (r=-0.209 and p=0.012). However, the relationship was not significant regarding the aspect of the social relationship (r=-0.148 and p=0.187).
Conclusion: the stroke patient caregivers' quality of life significantly decreases when their caregiving burden increases. Therefore, the health system mental, physical, social, and economic interventions and supports for the caregivers' empowerment can decrease care burden and increase the quality of life.

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Introduction

The increased burden caused by chronic diseases is on the major challenges the health systems across the world face with (1). At the moment, the deaths and disabilities caused by chronic diseases are more than those by infectious diseases in the world,

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except for the poorest countries (2). Stroke is one of the most common ones of these diseases which is the third cause of death in the developed countries, the second one in the developing countries, and the main cause of disability in adults (3, 4). It is because of the acute nerve damage caused when the blood supply to a part of the brain is interrupted and stopped or one of the feeding vessels in the brain tissue ruptures. The statistics show that 10 percent of the patients completely recover and 70 to 75 percent of whom face chronic disabilities such as motor sensory, physical, cognitive, and speech impairment (5, 6). Stroke annually happens in about 7.47 to 10.06 people per 1000 people above 65 years old in the world. The World Health Organization reported the incidence of stroke in about 130 people per 100000 people. In Iran, according to the study done by Azarpazuh et al. (2010) in Mashhad, the annual incidence of the first stroke is in 139 people per 100000 people (7-9).

Comprehensive care at post-stroke rehabilitation is very important. The caregiver burden is a multidimensional concept including physical, social, psychological, and financial aspects (10). The caregivers are prone to depression, sadness, chronic fatigue, insufficient sleep and rest, changes in social communication, changes in employment status, and economic, physical, and mental problems (6, 10-12). They are not trained by official and professional individuals and receive no money; Jen-Wen Hung refers to them as 'private caregivers' (A private caregiver is usually the spouse, child, stepchild, or a close friend of the patient) (13).

A study was conducted in Australia and indicated that the physical health of the caregivers of the patients with stroke significantly decreased in 3 weeks and 3 months after discharge (14). In the study done by Dalvandi et al. in Iran, many families mentioned that they have experienced many problems regarding the patient care and even left the patient because of insufficient social and financial support, lack of training programs, lack of access to rehabilitation services, and the patients' physical and mental problems (15, 16).

In the recent decades, the concept of the quality of life has become of great importance for quality assessment and health care results (17). The quality of life encompasses a vast range of concepts which beyond physical health. The important point regarding the quality of life is it's being multidimensional (18). According to the definition stated by the World Health Organization, the quality of life refers to a person's perception of his life in relation to purposes, expectations, standards, and his concerns about culture and value systems he lives with (19).

Some studies indicated that there the caregivers' burden has a relationship with stroke severity, low income, the caregivers' health level, care duration, and limited social relationship (20, 21). Akosile co et al. conducted a study in Nigeria and showed that 83.5 percent of the caregivers have a high caregiver burden level and their quality of life scores were significantly lower than the other caregivers (22). According to the researcher studies and experience, the caregivers of the patients survived from stroke in the East Azerbaijan province often do the caregiving by themselves because of the problems associated with distance from the center of the province, lack of sufficient training, and lack of support, treatment consistency, and rehabilitation by special centers in the province (23, 24). Therefore, regarding the study results indicating the caregivers' low quality of life, high incidence of stroke in Iran and especially in the East Azerbaijan province, and lack of research in this field in the country and the province, it is necessary to investigate the relationship between the caregiver burden and the caregivers' quality of life. As such, the results would be helpful in planning training, supportive, and preventive programs so as to decrease the caregiver burden and increase the caregiver's quality of life.

Method

This is a descriptive-correlational study which aims at investigating the relationship between the caregiver burden and the quality of life of the patients survived from stroke in Tabriz University of Medical Sciences clinics. The population included 120 caregivers of the patients survived from stroke and had at least a 3-month caregiving experience and were family caregivers (the main patient's caregiver and having a relation with the patient). These caregivers took care of only one patient who had a complete or relative dependence in daily activities, received no money, and accompanied the patient to the clinics for caregiving, treatment, and physiotherapy follow up. The sample with a confidence level of 95%, the power of 80%, regarding the previous studies (r=0.27), and using Gpawer3.1 software was selected as 105 people that was finally calculated as 120 people considering 20% decrease probability (25). The availability sampling was done after receiving the permission of the regional ethics committee of Tabriz University of Medical Sciences and the written consent of the participants through the Caregiver Strain Index (CSI), the Persian version of the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire and the demographic information form in 5 months. Furthermore, the participants were made sure that their information would be kept as confidential. WHOQOL-BREF questionnaire generally assesses the quality of life of the healthy people and patients (26). It includes four areas of physical health, mental health, social relationships, and environmental health in 24 questions (each of these areas respectively contain 7, 6, 3, and 8 questions). It contains two other questions which do not belong to any of the areas and generally assess the health status and quality of life. Therefore, this questionnaire contains 26 questions. Every area can obtain a score from 4 to 20; a higher score represents a better quality of life. Number 4 represents the worst condition and number 20 demonstrates the best condition. The scores were changed from 0 to 100 according to the table so as to make the discussion easier (27). The Caregiver Strain Index (CSI) was used to measure caregiving burden. It is an instrument which is used to rapidly identify the caregivers who have potential caregiving problem. This index includes 13 questions assessing the distresses related to caregiving. There is at least one item for each of the following areas: employment, financial status, physical status, social status, and time. Giving positive answers to 7 or more items indicates a high caregiving burden (28). The Caregiver Strain Index (CSI) has been used in many studies, but it is very limitedly used along with WHOQOL-BREF

simultaneously; the maximum relationship between the caregiver burden and quality of life has been done with Zarit Caregiver Burden Interview and CBS and the results are sometimes close to each other and sometimes different from each other. In addition to repeating the study of the relationship between the caregiver burden and quality of life with the instruments of WHOQOL-BREF and CSI, this study presents the results of the studies done by other instruments for comparison. Mo'meni (2009) quotes from Prattkin Jordan that the quality of life measurement in medical texts has been done through different attitudes, methods, and aspects. Hence, the range of the obtained scores is different (29-31). In this study, the validities of the questionnaires CSI and WHOQOL-BREF were determined by content validity and their reliability was determined through internal consistency (α-0.93 and 0.86). Data were analyzed using descriptive and inferential statistics (Pearson correlation) with the significance level of p<0/05.

Findings:

In this study, 120 family caregivers, mostly the children, took part. Women were twice as much as men. The mean and standard deviation of the caregivers' age was (41.9 ±12.38) (Table 1). Regarding the quality of life, the maximum mean belonged to the caregivers' physical health aspect and the minimum mean belonged to the environment aspect (Table 2). 40 caregivers had a caregiving burden lower than 7 (5.453 ±0.735) and 80 caregivers had caregiving burden equal to or more than 7 (8.876±1.653).

Table1. Demographic Information of the Patients Survived from Stroke

Variables	**Caregivers (percentage and frequency)**		
Marital status	Single	(72.5)	87
	Married	(23.3)	28
	Divorced	(2.5)	3
	Widow	(1.7)	2
Educational level	Uneducated	(6.7)	8
	Elementary	(14.2)	17
	High school	(26.7)	32
	BA and above	(24.1)	29
Income	High	(19.2)	23
	Low	(24.2)	29
	Average	(56.7)	68
Occupational status	Clerk	(20)	24
	Unemployed	(50.8)	61
	Retired	(3.3)	4
	Farmer	(2.5)	3
	herdsman	(1.7)	2
Place of living	City	(70)	84
	Village	(30)	36
Home	Rental	(17.5)	21
	Personal	(82.5)	99

Table2. Mean and Standard Deviation of the Quality of Life Dimensions

The Quality of Life Dimensions	**Mean and SD**
Physical health	79.74 ±16.48
Mental health	68.55 ±22.19
Social relationships	67.01±20.76
Environmental health	57±16.74

The results of this study indicated that there is a significant relationship between the caregiver strain index and the quality of life dimensions, except for the social relationships aspect. There is a weak relationship regarding the social relationships aspect.

Table3. The Relationship between the Caregiver Strain Index and the Quality of Life Dimensions

The Quality of Life Dimensions	**CSI(TOTAL)**		**CSI2(CSI≥7)**	
	Pearson coefficient	Sig.(2-tailed)	Pearson coefficient	Sig.(2-tailed)
Physical health	-0.374	**000	-0.405	**000
Psychological health	-0.245	*0.007	-0.227	*0.042
Environmental health	-0.229	*0.012	-0.209	0.061
Social relationships	-0.063	0.497	-0.148	0.187

**Significance at the level of 0.01 (2-tailed). * Significance at the level of 0.05 (2-tailed)

Discussion: a caregiver plays an important role in improving the patient's quality of life providing that he himself has a desirable physical and mental health. Reviewing different studies indicated that the mean score of the quality of life dimensions are sometimes similar to each other and sometimes different from one another. However, in most of the studies, the minimum mean score respectively belongs to physical health, mental health, social relationships, and environmental health. In the present study, the mean score of the caregivers' quality of life dimensions is average to high, but the environmental health has the minimum score. The results are contrary to the study done by Michele Baumann et al. and other studies (8, 31, 32) and consistent with the studies done by Dong-Ho Choi et al. in Korea, Deepak Ganjiwale in India, Yeon-Gyu Jeong in Korea, and Mary Lícia de LimaI in Brazil (26, 33-35). The analysis of the items of this dimension in this study shows that more than half of the caregivers are dissatisfied with lack of access to transportation and commuting facilities as well as having opportunity to do things they like; more than half of them do not have access to news and information and a quarter of whom are dissatisfied with the living place condition and facilities as well as having access to health services. They tolerate a great deal of burden. Therefore, it should be of the planning priorities to eliminate these problems and obstacles, especially in rural areas and for suburban caregivers so as to decrease their caregiving burden and increase their quality of life. In this study, the mean score of question 1 in WHOQOL-BREF was 66.4 and that of question 2 was 65.8; it is consistent with the study done by Mary Lícia de Lima in São Paulo in terms of the satisfaction with quality of life, but there is a mean difference regarding the satisfaction with health status (35).

In this study, the maximum mean belongs to physical health which is inconsistent with many of the studies (8, 32, and 34) but consistent with the study conducted by Lima MLd et al. in Brazil and similar to the study done by Michèle Baumann et al. in Luxembourg (2012) in terms of the amount of mean (31, 35). The reason for highness of the score of this aspect can primarily be because of the young caregivers and it is mentioned in different studies (21, 29, and 36). Nevertheless, Rajesh Kumar et al. believe that being a young caregiver increases the caregiving burden (32). The second reason may be the child relation of the caregivers who have less caregiving responsibility, anxiety, stress, and physical and mental illness experience and are more educated and successful in receiving caregiving training, compared to the spouses (21, 29, and 36). There is an inverse significant relationship between the caregiver burden and physical health aspect which is consistent with the study of Rajesh Kumar et al. (2015) (8).

In this study, the score of the mental health aspect is average and above and has an inverse significant relationship with the caregiver strain index; it is consistent with the studies of Rajesh Kumar and Deepak Ganjiwale in India and that of Rinu Susan Raju (32, 34, and 37). The divorced and widow caregiver women tolerated a higher caregiving burden in this study and had a lower quality of life compared to the men. The divorced people's lack of support from society and sometimes from the family decreases their confidence and increases their caregiving burden. Holly Blake et al. in Nottingham mentioned that the caregiver burden has a relationship with low confidence, decreased positive feelings, and increased negative feelings. Therefore, all dangerous factors decreasing the caregivers' quality of life which can be corrected by health care system and cultural norms need to be identified and basic plans should be adopted so as to eliminate these problems (38). Regarding this aspect, the caregivers answered the question 'Do you feel disappointed and anxious?' with sometimes and most often (71 percent) which had an average and above-average mean and standard deviation (1.04 ±3.275); it is consistent with the studies of Emily Mccullagh et al. in King's College London, Mary licia de lima et al. in São Paulo University, and Michele Baumann (31, 35, and 39). However, it is slightly different from the study conducted by Crystyna Jaracz et al. in Poland which mentioned the depression signs in 43 percent of the samples; but, the mental health aspect has similar results (40). Holly Blake et al. conducted a study through the instrument of CSI and reported six months after caregiving that most of the caregiver spouses gave a positive answer to the items of the feeling of anxiety, personal program change, worrying behaviors, and feeling of limitation. Their quality of life in the mental health aspect also decreased which is consistent with all items in the present study except for worrying behaviors (38).

In the study conducted by HASSAN.S et al. in the physiotherapy center South Africa, 91 percent of the caregivers gave a positive answer to question 8 of CSI which was related to the caregivers' emotional changes and modifications and indicated that their quality of life decreased; it is close to the results of the present study (41). Gbiri Caleb Ademola et al. in Nigeria stated in their study that the caregivers are not ready to be worried about caregiving and experience caregiving burden and mood distress which affect their quality of life (10). Therefore, the caregivers need to be mentally supported from the beginning

of the caregiving and the caregivers suffering from mental problems should be prohibited from caregiving until they are completely recovered.

In this study, there is an inverse insignificant relationship between the caregiver burden and social relationships aspect. The amount of the total satisfaction with family support is 70 percent which is consistent with the study of Emily Mccullagh et al.; they indicated that in the first year of caregiving, the lack of family support increases the caregiver burden and the social services support slightly affects the caregiver's burden and quality of life but is effective in reducing basic needs. The studies done by Rajesh Kumar and Rinu Susan Raju are also confirmed (32, 37, and 39). It is also consistent with the study conducted by Yeon-Gyu Jeong et al. in Korea which had the maximum average score. This issue can be related to cultural norms in Iran as it is in Korea through which the families consider it a duty to support and care the members of the family and do not even demand wages and rewards (26). Akosile Christopherj et al. conducted a study in which 70.3 percent of the caregivers were the immediate members of the family (spouse, child, sister, and brother) and needed to be supported (22). In the study done by Mary licia de lima, it was made clear that the quality of life in the area of social relationships in the presence of the caregiver is more than that in the absence of the caregiver; this somehow confirms the high mean score of this aspect. According to WHOQOL-BREF questionnaire, the area of social relationships is related to three issues of individual communication, family support, and sexual activity. The caregivers found it difficult to answer the question of sexual activity since no option was available for those who do not have a sexual relationship and they did not know what to answer while taking part in this study. It seems that in the present study, like the previous ones, culture and religious beliefs are the greatest and most important cause for this problem; therefore, it is recommended to make a solution for the items of this aspect in the next studies (35).

Bum-Chul Jung et al. conducted a study and indicated that the caregiving process negatively affects the caregivers' social activities, leisure time and fun, and family relationships. Although the caregiver burden does not significantly affect the aspect of social relationships in this study, it is necessary to counsel, train, and socially support the caregivers so as to reduce their depression and caregiving burden and preserve their health and quality of life (6).

In this study, most of the caregivers were from Tabriz and its suburbs who had a better condition regarding the access to rehabilitation facilities and therapeutic and care centers compared to the suburban caregivers. It is suggested that a study be conducted with more samples and from different cities of the province.

Conclusion: in the present study, although the caregivers' quality of life average score is average and above, there is a significant relationship between the caregiver burden and the quality of life dimensions except for the social relationships aspect. Regarding the absence of the caregiver supporting centers in the country and the province, it is proposed to make some interventions and supports to mentally, physically, socially, and economically empower the caregivers by the health system because the caregiver empowerment decreases the caregiving burden and increases the quality of life.

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